



# EPF Campaign on Patient Empowerment: Roadmap for Action

This campaign is a joint initiative of the European Patients' Forum and the Robert Bosch Stiftung with the support of Amgen, GSK and MSD.

Robert Bosch **Stiftung**

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## Introduction

Patient empowerment is at the root of the European Patients' Forum's vision and embedded in our mission, as stated in our Strategic Plan 2014-2020:

### **Goal 4: Patient Empowerment**

To promote the development and implementation of policies, strategies and healthcare services that empower patients to be involved in the decision-making and management of their condition according to their preference, whilst raising awareness about their rights and responsibilities.

The term patient empowerment is often used interchangeably with others such as patient involvement or patient-centred care. Sometimes, it is perceived simply as the use of technology by patients. A recent EPF briefing paper (2015) clarifies these concepts from the patient perspective.<sup>1</sup>

We use the following definition of empowerment, applied to patients:

Empowerment is “a multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important.” Collective empowerment is “a process through which individuals and communities are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs.” (Adapted from [JA-PaSQ](#))

Aspects of empowerment can include self-efficacy, self-awareness, confidence, coping skills, health literacy, etc. It can be seen as a goal as well as a process, and it is a complex concept that is context-dependent. Patients' empowerment is affected by the people, processes, organisations and structures that they come into contact with and can fluctuate with time.

In healthcare, at the individual level, (dis)empowerment often manifests in the patient-professional relationship; at organisation level, in care processes or the design of the care environment. At macro-level, factors that contribute to (dis)empowerment can include (the lack of) information to patients, implementation of patients' rights, opportunities for patients to participate in health policy, and transparency of the system.

## Patient empowerment and the challenge of chronic diseases

Chronic diseases are conditions of long duration and generally slow progression, which result in significant morbidity and loss of healthy life years. They represent the major share of the burden of disease in Europe<sup>2</sup>, affecting more than 80% of people aged over 65. An estimated 70-80% of healthcare costs – around €700 billion – are currently spent on chronic diseases.<sup>3</sup> Given that the ageing population of Europe, addressing chronic diseases is one of the key objectives of EU health policy for the next years.

For an effective strategy on chronic diseases, all the aspects of physical and mental health including health promotion, primary and secondary prevention, and patient-centred chronic disease management should be seen holistically as a continuum where all the elements play a complementary and mutually supporting role.

The recognition that healthcare systems should change to improve not only their cost effectiveness and long-term sustainability but also their effectiveness in providing high-quality care, represents a paradigm shift. Care will need to shift from an acute, hospital-centric environment to a community-based, integrated, longer-term model. In this model, patients are no longer passive recipients of care but active partners and ultimately “co-producers” of health.<sup>4</sup>

There is a political acknowledgement at EU level that patients should be “at the centre” of healthcare systems and that to achieve this, patients' representative organisations should be part of healthcare-related policy and decision-making.

## Patient Empowerment – a key pillar for quality, patient-centred sustainable healthcare systems of the future

Citizens' empowerment is a core value of the EU Health Strategy Together for Health. In 2006 the Council recognised patient involvement as one of the shared operating principles of European health systems. EU co-funded projects, such as Value+, PatientPartner and EUPATI, have shown the benefits of patient engagement. Patient-centred chronic disease management with focus on patient empowerment was identified as a priority in the reflection process on chronic diseases initiated.<sup>5</sup> Patient-centredness is recognised as a core component of quality care.<sup>6</sup> Patient-centred care models have been shown to be cost-effective as well as improve the patient experience and health outcomes.<sup>7</sup> Patients living with chronic conditions are “experts by experience” whose perspective on disease and care is unique. When they are genuinely involved in healthcare decisions and their preferences are listened to and acted on, the result is better health outcomes, more engaged patients and, potentially, lower costs.<sup>8</sup>

Despite this accumulating evidence base, there is still no consistent and comprehensive approach in Europe to patient empowerment. To some extent this has no doubt to do with the different structures and cultures of European health systems, but also lack of awareness and resources; lack of knowledge on how to meaningfully involve patient groups; and a patient community with different levels of capacity across the EU.

Collective patient empowerment, through the meaningful involvement of patient representatives and organisations in health policy, service design and evaluation with the aim to improve the system, will be the key to fostering patient empowerment in all EU health systems. One of the core actions we envisage is a European Strategy on patient empowerment, as evidenced by EMPATHIE.

### Why we developed this Roadmap

This Roadmap for Action on Patient Empowerment has been developed by the European Patients' Forum in the context of our Campaign on Patient Empowerment.<sup>9</sup> It accompanies the [Charter on Patient Empowerment](#), proposing a series of concrete actions towards realising the fundamental principles expressed in the Charter. The Roadmap is divided into *eight priority areas*, reflecting the priorities of the Charter as well as recommendations arising from the [EMPATHIE study](#) (2014).

## How to use this Roadmap

The EMPATHIE study conducted a stakeholder survey, which confirmed a strong interest among all key stakeholders – health professionals, patient organisations, policymakers, regulators, academia and industry – to collaborate at European level towards the objective of achieving concrete improvements in healthcare, taking as a starting point patients’ self-defined needs and expectations. The study recommended first and foremost the development of a *European strategy on patient empowerment* to inform policy, practice and further research. We believe this Roadmap should be used to identify key areas to be included in such a strategy.

We recognise that no approach on its own will be capable of addressing all aspects of empowerment, in all different contexts as empowerment is complex and influenced by many factors. The priority areas and actions in this Roadmap are highly complementary and can point towards multiple paths towards the goal of achieving European health systems that are high-quality, patient centred, participatory and sustainable.

In many cases there is a need for further research to understand the state-of-the-art and identify gaps. In some cases, there is an established EU framework for a given policy area. In other cases, there is not. This means that stakeholders can take action to shape the EU agenda from the bottom up. However, we also believe that top-down policies support is needed – both from the European Commission and the Parliament, and from national governments.

The Roadmap is intended to provide direction and inspiration for action. We have not indicated any specific timelines, as we wish to take a long-term view. We also have not provided specific instructions on “who” should take which action: we believe that the engagement of a wide range of stakeholders – patients, policymakers, different health/social care professionals, and sometimes commercial actors – is required in each area. There is a need to develop a new, much more collaborative mind-set to cut through existing “silos” and develop solutions together – and always with patients and their representative organisations as partners.

## Why we developed this Roadmap

We are aware that in many of the key areas identified in this Roadmap, there are existing examples of good practice and innovation. We continue to collect these good practices and case studies, with the aim of making them available at a later date. The Roadmap in itself may also be updated if necessary, to include case studies.

**Do you have a good practice that you wish to share? Do you have an idea for collaboration or wish to engage further in developing a certain action area?** Contact us: [policy@eu-patient.eu](mailto:policy@eu-patient.eu)

We would love to hear from you!

## Priority area 1: Health literacy and information

Patients in 21<sup>st</sup> century society are increasingly asked to take responsibility for their own health and well-being, while confronted with huge amounts of complex and sometimes contradictory information. In this context, health literacy is both a dimension of empowerment and a critical strategy towards empowerment and health equity.<sup>10</sup>

Health literacy encompasses accessing, understanding and evaluating health-related information, as well as transforming it into appropriate actions in everyday life.<sup>11</sup> Low health literacy has a negative impact on people's health and is related to increased costs to the healthcare system.<sup>12</sup>

The Third Health Programme states that patients “need to be empowered, inter alia by enhancing health literacy, to manage their health and their healthcare more pro-actively, to prevent poor health and make informed choices. The transparency of healthcare activities and systems and the availability of reliable, independent and user-friendly information to patients should be optimised.”<sup>13</sup> Yet, despite the accumulating evidence-base<sup>14,15,16</sup> there is no coherent EU policy on health literacy or health-related information for patients and citizens. A set of quality principles for information to patients was developed as far back as 2008, but is not systematically used to inform policy or practice.<sup>17</sup>

### Priority actions:

- ➔ *Health literacy as policy priority.* Promote access to accurate, objective, unbiased, user-friendly and scientifically up-to-date information relevant to patients' needs, on all aspects of health from promotion and prevention to disease (self-)management and therapeutic options, based on patients' identified needs and analysis of gaps.
- ➔ *Analysis of EU policy options.* A study should be funded to analyse all current EU legislative and non-legislative frameworks pertaining to information to patients, providing an overview of existing resources and their implementation across the EU, as well as gaps and policy options for further action.
- ➔ *Patients' access to their own health records.* Empowerment starts with having and understanding one's own medical file. As part of the monitoring of the implementation of the directive on cross-border healthcare, the European commission should monitor how the patients' right to access their own health records is implemented in practice across the EU, and recommend actions for improvement.
- ➔ *Health literacy in all policies.* Health literacy should be a part of all policies, including education, food, urban planning, social protection, and employment. A symposium could be held at European level on “health literacy in all policies”. Patients and particularly young patients' groups should advocate for inclusion of health literacy in schools.
- ➔ *Research to inform policy.* In order to have comparative data and monitor changes over time, the European Commission should conduct a regular health literacy survey across the EU, using the validated instrument from the EU Health Literacy Survey (HLS-EU).

## Priority area 2: Professional skills and shared decision-making

Shared decision-making is an intrinsic part of patient empowerment. To become engaged in managing their health, patients need to be empowered to make decisions about their care in partnership with members of their healthcare team. Shared decision-making is, however, the least researched area of patient empowerment.<sup>18</sup>

Patient-centred skills such as shared decision-making, listening, supportive and effective communication, empathy and partnership are “soft skills” that are not specific to any medical condition. New roles and skills may also need to be developed based on patients’ expressed needs, values and preferences; such as care co-ordination, coaching, or patient advocacy.

To implement patient-centred, integrated chronic disease management, the training of future professionals will need to be adapted, but also the attitudes and skills of currently practising professionals will need updating. At the same time, the working environment sometimes does not encourage health professionals to engage with patients meaningfully (e.g. due to pressures of time or workforce shortages).

The Expert Panel on Effective Ways of Investing in Health (EXPH) in its recent report made a high-priority recommendation “to promote the training of health professionals in their new role as ‘trainers’ for patients with chronic conditions and in addition develop ways, means, time and motivation for professionals to learn better communication skills to engage and involve patients in their care.”<sup>19</sup> Patients should be much more involved in professional training and the development of curricula than they are now.

### Priority actions:

- ➔ *Core set of professional skills for patient-centred healthcare.* A set of “core competences” for soft, non-disease specific skills – particularly communication and patient engagement skills – should be developed that can be integrated into professional training and curricula, taking into account already existing resources, such as the Canadian CANMEDS20 framework. An EU-wide network could be established involving patients and professionals’ organisations and academia as well as national policy-makers, with support from the EU Health Programme.
  - CME/CPE credits should be made available for professionals’ participation in patient-led activities.
- ➔ *Reinforce the evidence-base on shared decision-making.* Further research should be supported on shared decision-making and the use of patient decision-aids, particularly regarding non-disease specific aspects that could be transferable.
  - This should include a multi-country comparative survey to know what works from the perspective of patients and of healthcare professionals and how different factors such as age, gender and health condition impact the use of such tools.
- ➔ *Coherence on policy.* The synergies among existing EU frameworks, such as the EU Action Plan on the Health Workforce, the European Commission’s Expert Group on Investment in Health, and the Expert Group on Patient Safety and Quality of Care, should be explored to identify opportunities for specific actions to support and co-ordinate national policy and share good practice.

## Priority area 3: Self-management support

Patients with chronic conditions manage their condition mostly themselves in the home and in the community.<sup>21</sup> They do this with and without support. However, to maximise the benefit of self-management patients do need effective support. This can be, but is not necessarily, through the use of technology.

EPF sees self-management in its wider sense as a holistic approach providing the appropriate support and tools for each person's individual needs and preferences. Through this approach, patients can develop the confidence, self-efficacy and skills to take control of the daily management of their illness and attain the greatest possible quality of life. In this sense, self-management support also aims to make the best use of all available resources in the system – including the “most underused resource”: the knowledge, skills and motivation of the patient.<sup>22</sup>

There is good evidence that supported self-management improves health outcomes and reduces costs.<sup>23</sup> The importance of self-management support has long been understood, and in many disease areas (e.g. diabetes, respiratory diseases) models and tools have been promoted and researched for decades.<sup>24,25,26</sup> Yet, it is unclear to what extent such services are available to patients in different Member States and disease areas. To some extent this may be filled by to currently ongoing studies – the PISCE and PRO-STEP tenders – which are however limited in their scope. The studies will produce results by 2018.

### Priority actions:

- ➔ *Better understanding of the state of the art of self-management.* A cross-Member State, cross-disease study should be conducted to provide a better understanding of what patients' needs for self-management support are, to what extent they are met, and how many patients have access to evidence-based self-management education and support programmes.
- ➔ *Promote self-care and self-management in policy and practice.* Provisions for policy action informed by the forthcoming recommendations from the PISCE and PRO-STEP studies should be planned for and integrated within the Health Programme.
- ➔ *Promote health literacy and patient-professional communication.* Implementing the actions under priority area 1 and 2 are necessary to support optimal self-management.
- ➔ *Self-management as part of integrated care.* Self-management should be seen as an essential part of all integrated care approaches – see priority area 6.



## Priority area 4: Patient-driven technology solutions

eHealth and mHealth are often seen as potential solutions to increase efficiency and cut costs, but they also have considerable potential to support patients' empowerment and adoption of an active and responsible role for their health. ICT tools can provide self-management support and motivation, remote monitoring through wearable technology, and data from patients' observations to a global electronic health record.

Mobile apps can potentially blur the traditional distinction between clinical care by physicians, and self-care.<sup>27</sup> However, most available tools at the moment target the consumer market; patients who use apps for disease management are a minority, and they often do not find it easy to know which tool would be right for them. The European Commission's eHealth Action Plan (2012) and the Chain of Trust project run by EPF (2013) identified lack of trust and lack of training as key barriers to uptake of technology.<sup>28</sup>

Often, new devices are introduced as "empowering" patients, but technology in and of itself is not empowering. Often, patients are not consulted in the development of the "innovation" and there is no evidence that the new tool actually meets their needs. In order for these tools to realise their potential, development needs to become user-driven and patient-driven, rather than technology-driven. Capacity-building and awareness raising is needed to ensure that developers know how to involve patients properly from the start.

### Priority actions:

- ➔ *Identify users' priorities.* Based on findings to date, there should be more targeted research and development to address the lack of user-friendly tools and services. This should be addressed in a collaborative effort by patient organisations, companies and researchers.
- ➔ *Ensure meaningful patient involvement from the start.* Guidance on the quality and development and mobile tools should include provisions for meaningful patient involvement from the outset of the process. Existing guidance for software developers for inclusivity towards people with disabilities should be taken into consideration.
- ➔ *Identify the added value.* Indicators should be developed at EU level to measure the "added value" of ICT applications – both from the patients' perspective and the health systems' perspective, to ensure investment in tools that provide maximum value for patients and society.
- ➔ *Education and training for trust.* Education resources and tools should be developed to support the use of eHealth and mHealth tools, both for patients and for different health professionals.
- ➔ *Policy support.* Platforms such as the European Innovation Partnership on Healthy and Active Ageing (EIP-AHA) could provide a framework for the development, sharing *and evaluation* of patient-driven solutions specifically to support patient empowerment.

## Priority area 5: Patient involvement in patient safety

Patient safety is both a goal (a state of being that is free from harm) and a practice (processes and structures that aim to make healthcare safer). Patient safety is a fundamental attribute of quality of care. Safety covers everything from harm caused as a result of a wrong diagnosis, clinical procedure or decision, to the side-effects of drugs, hazards posed by medical devices or sub-standard products, human shortcomings, and system errors, in all kinds of health care settings (see EPF “Briefing paper on patient safety”, [2016](#)).

Addressing safety means ensuring that the healthcare system or organisation takes all possible measures to prevent vulnerabilities, and when errors do happen they are recognised and fully investigated and lead to action in order to prevent future errors. Developing a “patient safety culture” is vital and this involves the recognition that safety is everyone’s business – including patients and their families’.<sup>29</sup>

Patients can get involved by becoming health literate and actively co-managing their own health. They can also help improve services overall to make them more patient-centred. Involving patients implies a change in medical culture where professionals, managers, and policy-makers listen to patients, take their observations and concerns seriously, accept them as equal partners and encourage feedback and involvement at all levels – without shifting the burden of responsibility inappropriately on patients. Transparent and comparable information in lay friendly language and format is one important tool to empower patients and supports continuing improvement and easier navigability of the system.

### Priority actions:

- ➔ *Provide information and resources to empower patients.* Member States should provide understandable information about safety and quality of care that enables patients to make comparisons and meaningful choices, including between care providers and between Member States.
- ➔ *Improve the handling of adverse events.* Healthcare providers should communicate openly and honestly with patients and their families, providing full explanations and a “human response” as well as taking concrete action to improve safety. Procedures for complaints and redress should be fair, accessible and transparent. EPF’s conference report on patient safety (2016) will make recommendations.
- ➔ *Enhance the capacity of patients to contribute to safety.* EPF will set up a working group in 2017 involving patient representatives and other experts to develop a set of “core competencies” for patients and families in the area of patient safety.
- ➔ *Involve patient organisations in national policy.* All Member States should involve patient organisations and representatives in the development of policies and programmes related to patient safety, including prevention of healthcare associated infections, as required by the EU Council recommendation on patient safety from 2009.
- ➔ *Make safety an EU policy priority.* Sufficient resourcing for a permanent EU framework for collaboration on patient safety should be ensured in the EU Health Programme. This network should involve Member States and all relevant stakeholders, building on the achievements of the PaSQ Joint Action.

## Priority area 6: Patient-centredness in healthcare

*Patient or person-centredness* is increasingly recognised as a core component of quality in healthcare. Patient-centredness involves not only being responsive to patients' needs and preferences, but also empowering patients and their families to enable the participation as active and equal participants in the care process. It also requires a seamless integration of the different aspects of health (and social) care around families' needs.

An accurate elicitation of the patients' needs and preferences is a fundamental starting point for a re-design of care in order to become more patient-centred. Indicators for healthcare quality exist, such as those collected by the OECD and the European Community Health Indicators (ECHI); however, there is currently no agreed way of measuring patient-centredness or patient empowerment – partly because the concept is not easy to quantify.

There is a need for more systematic understanding about how patients define “quality” in healthcare, and how patient-centredness could be measured. The patient experience is an important aspect that should be included beside clinical indicators in evaluations of healthcare quality. This implies meaningful, and if necessary qualitative, measures based on patient feedback that can be analysed, acted upon and actually lead to better care. For example, many initiatives and projects are ongoing across the EU and internationally, and numerous initiatives at local level are promoting and implementing *integrated care*<sup>30</sup>; but they do not always involve patients meaningfully or recognise them as equal partners *in* the care team (EPF, [2009](#), p.56).

### Priority actions:

- ➔ *Recognise patient-centredness as a key performance indicator.* Patient-centeredness should be included as a key metric under the EU Health System Performance Framework (HSPA). Appropriate indicators, including patient experience measures, should be selected and new ones developed with patients' involvement where necessary, including qualitative evidence.
- ➔ *Enable patient feedback.* Healthcare organisations and systems should implement mechanisms to systematically collect positive and negative feedback from patients and families. Existing good practices should be collected from member states, healthcare organisations and professional societies.
- ➔ *Promote systems innovation.* EU research funding should support research on innovative healthcare organisation and delivery models, such as patient perspectives on integration of care, participatory medicine, patient involvement and organisational culture change.
- ➔ *Implement good practices in integrated care.* Sharing and implementation of good practices on integrated care models and pathways, where the patient and family participate as full and supported partners, and which include self-management and link healthcare with social care and support.

## Priority area 7: Patient involvement across the R&D lifecycle

Advances in medicine are only possible with the voluntary participation of patients. Patients therefore have a moral right to be involved in how research is developed, managed and evaluated. Patients' experiential knowledge is also an important complement to researchers' scientific knowledge, as their priorities are often different from those of researchers, medical professionals or industry.

To ensure that innovation brings real value to patients, patient involvement needs to be adopted as a strategic approach and integrated across the entire innovation chain at EU and national levels. There is a need to develop frameworks for ensuring that patients' priorities guide R&D.<sup>1</sup>

EU research programmes encourage but do not mandate patient involvement. In some Member States, such as the UK, a requirement for patient (and public) involvement has become universal for funding applications at least in translational research, but the extent of involvement is variable across Europe. Gaps remaining understanding what is the most appropriate form of involvement for different types of research and for different patient groups. In medicines regulation, the European Medicines Agency (EMA) has a well-developed framework for involving patients and consumers.<sup>31</sup>

As patients' needs go beyond medicines and include other therapeutic options, social and community services and peer support, innovation should be encouraged in this wider sense, including better ways of structuring and delivering healthcare, social innovation, and the development and effective use of new user-driven technologies (see priority areas 4 and 6).

### Priority actions:

- ➔ *Framework for meaningful patient involvement.* A framework should be developed for meaningful patient involvement across the innovation chain, in collaboration with the European Commission – the Innovative Medicines Initiative, DG Sante, DG Grow, and stakeholders – from priority setting in research through regulation, Health Technology Assessment, pricing and reimbursement, and the collection and use of patients' data.
- ➔ *Prioritise patient needs in research funding.* Both academic and industry-led research should prioritise issues that patients consider most important; research applications with meaningful patient involvement built into the research questions and protocols should be prioritised for funding.
- ➔ *Build capacity.* There should be continued emphasis on patient education by provision of up-to-date, evidence-based and unbiased information, building on the achievements of the EUPATI project. Equally, capacity-building is needed for institutions wishing to involve patients.
- ➔ *Adopt good practice.* The European Medicines Agency's principles of patient involvement should be adopted/adapted by national Medicines Agencies, particularly in Member States where there is currently little patient involvement.

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<sup>1</sup> Priority Medicines for Europe and the World Update Report, 2013, available at [www.who.int/medicines/areas/priority\\_medicines/en/](http://www.who.int/medicines/areas/priority_medicines/en/)

## Priority area 8: Patient involvement in health policy

Patients' participation in health policy is both a fundamental aspect of patient-centred healthcare (IAPO, [2006](#)) and an expression of the transparency and accountability of the system towards its users. Patient organisations can channel the collective voice of patients into effective policy advocacy, whether at local, regional, national, EU or global levels. They also often provide peer support for patients at the grassroots level.

Patient organisations should be recognised as key stakeholders and members of the public health community. Policies and research which affect patients directly or indirectly should be developed with the meaningful participation of patient organisations. In order to provide patient organisations with sufficient resources and skills to accomplish this role, and to ensure their independence, they need to have access to an appropriate mix of funding sources, including public funds.

### Priority actions:

- ➔ *Patient empowerment strategy.* A coherent strategy should be developed at EU level to drive patient empowerment and participatory health systems, including an action plan for health literacy and strategies for vulnerable groups. The process should be coordinated by the European Commission with the involvement of patient organisations.
- ➔ *Support for EU-level patient organisations.* A strategy should be developed and implemented for sustainable support through core grants, including adjustment of financial criteria to enable more patient groups to become eligible for EU funding and a management process that is optimally supportive of non-governmental organisations.
- ➔ *Support for national patient organisations.* Member States should explore together with patients and the private sector possible innovative and ethical ways of funding patient organisations from multiple sources, so they can accomplish their advocacy role effectively at national level whilst maintaining their independence.
- ➔ *Repository of good practices.* Good practices and initiatives on patient empowerment and patient involvement should be made available in an easily accessible online repository with information, experiences, tools and resources. This could be accomplished as a multi-stakeholder project funded through the EU Health Programme or Horizon 2020.

## Notes and references

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- <sup>1</sup> EPF Background Brief: Patient Empowerment (May 2015). Available at [www.eu-patient.eu/globalassets/campaign-patient-empowerment/briefing\\_paperpatient-empowerment\\_final\\_external.pdf](http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/briefing_paperpatient-empowerment_final_external.pdf)
- <sup>2</sup> Herein after 'Europe' substitutes the European Union, as in certain contexts it is more appropriate to refer to Europe in geographical terms.
- <sup>3</sup> Final report of the reflection process: Innovative approaches for chronic diseases in public health and healthcare systems, 11 November 2013
- <sup>4</sup> e.g. Realpe and Wallace, 2010
- <sup>5</sup> As in reference no. 3
- <sup>6</sup> R Jayadevappa and S Chhatre, "Patient Centered Care - A Conceptual Model and Review of the State of the Art", *The Open Health Services and Policy Journal*, 2011, 4, 15-25)
- <sup>7</sup> Parsi et al. 2011, Olsson et al. 2009, Mulley et al. A 2012
- <sup>8</sup> Mulley et al. "Patients' preferences matter: Stop the silent misdiagnosis". The King's Fund, 29 May 2012; Arterburn et al. "Introducing decision aids at Group Health was linked to sharply lower hip and knee surgery rates and costs", *Health Aff (Millwood)*. 2012 Sep;31(9):2094-104; Veroff D, Marr A, Wennberg DE: "Enhanced support for Shared Decision Making Reduced Costs of Care for Patients with Preference-Sensitive Conditions". *Health Affairs*, February 2013, vol. 32, no. 2, 285
- <sup>9</sup> The EPF Charter is available at: <http://www.eu-patient.eu/campaign/PatientsprescribE/charter-on-patient-empowerment/>
- <sup>10</sup> EMPATHiE. Empowering Patients in the Management of Chronic Diseases. Final report, 10 November 2014; Wallerstein, N (2006) "What is the evidence on effectiveness of empowerment to improve health?" Copenhagen, WHO Regional Office for Europe (Health Evidence Network report).
- <sup>11</sup> Sørensen et al. "Health literacy and public health: A systematic review and integration of definitions and models", *BMC Public Health* 2012, 12:80.
- <sup>12</sup> Eichler, K et al. (2009). "The costs of limited health literacy: a systematic review", *Int J Public Health*, 2009;54(5):313-24; World Health Communication Associates 2010; WHO Europe 2013, Health Literacy: The Solid Facts.
- <sup>13</sup> Regulation (EU) No 282/2014, recital 12
- <sup>14</sup> Countries: Austria, Bulgaria, Germany, Greece, Ireland, The Netherlands, Poland and Spain. HLS-EU Consortium (2012): Comparative Report of Health Literacy in Eight EU Member States. The European Health Literacy Survey HLS-EU (first revised and extended version, dated 5 July 2013).
- <sup>15</sup> "Study on sound evidence for a better understanding of health literacy in the European Union". RfS Chafea/2014/health/01. Final Report, June 2015.
- <sup>16</sup> See for example: [www.irohla.eu/home/](http://www.irohla.eu/home/) and [www.diabetesliteracy.eu](http://www.diabetesliteracy.eu)
- <sup>17</sup> See the "Core quality principles adopted by the EU High-Level Pharmaceutical Forum (2008) available at <http://ec.europa.eu/DocsRoom/documents/7593?locale=en>
- <sup>18</sup> EMPATHiE study, final report, 2014.
- <sup>19</sup> "Future EU Agenda on quality of health care with a special emphasis on patient safety". Final opinion, EXPH, 9 October 2014, p. 71.
- <sup>20</sup> <http://canmeds.royalcollege.ca/>
- <sup>21</sup> <http://www.eu-patient.eu/whatwedo/Policy/A-Z-list-of-topics/>
- <sup>22</sup> EPF position paper on adherence and concordance (2015)
- <sup>23</sup> De Silva (2011) "Evidence: Helping people help themselves. A review of the evidence considering whether it is worthwhile to support self-management". The Health Foundation, 2011.
- <sup>24</sup> E.g. in management of allergy, asthma and COPD in the Nordic countries and the UK (European Federation of Allergy and Airways Disease Patients' Associations).
- <sup>25</sup> Bodenheimer et al (2002) "Improving primary care for patients with chronic illness. The chronic care model, part 2." *JAMA* 2002; 288: 1909-1914; Wagner, EH (1988) "Chronic disease management: what will it take to improve care for chronic illness?" *Eff Clin Pract.* 1998 Aug-Sep; 1(1):2-4.
- <sup>26</sup> <http://patienteducation.stanford.edu>
- <sup>27</sup> COM(2012)736 final, p. 9

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<sup>28</sup> See also project “Chain of Trust” final report, 2013 at [www.eu-patient.eu](http://www.eu-patient.eu)

<sup>29</sup> A useful definition of patient safety culture: “A safety culture is where staff within an organisation have a constant and active awareness of the potential for things to go wrong. Both the staff and the organisation are able to acknowledge mistakes, learn from them, and take action to put things right. To reduce the likelihood of incidents occurring, patient safety needs to be addressed at an institutional level, ‘from trust board to ward’, as well as by designing out errors in processes and equipment.”

(Source: [www.nrls.npsa.nhs.uk/resources/patient-safety-topics/human-factors-patient-safety-culture/](http://www.nrls.npsa.nhs.uk/resources/patient-safety-topics/human-factors-patient-safety-culture/) )

<sup>30</sup> For example: <http://integratedcarefoundation.org/our-work> and

<http://integratedcarefoundation.org/events/icic16-16th-international-conference-integrated-care-barcelona>

<sup>31</sup> Available at:

[www.ema.europa.eu/ema/index.jsp?curl=pages/partners\\_and\\_networks/general/general\\_content\\_000317.jsp&mid=WC0b01ac058003500c](http://www.ema.europa.eu/ema/index.jsp?curl=pages/partners_and_networks/general/general_content_000317.jsp&mid=WC0b01ac058003500c)